

PREMARITAL GENETIC SCREENING AND ITS RAMIFICATIONS FOR THE JEWISH COMMUNITY

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For most of history, Jewish people have avoided intermarriage with members of other religious and ethnic groups. This may be attributed to both the conscious observance of the Torah commandment that states, “You shall not intermarry with them; you shall not give your daughter to his son, nor take his daughter for your son” (Deuteronomy 7:3), as well as the social and geographic isolation of Jews from secular society throughout the ages. Such reproductive patterns are no different from any other group of people or animal species that practices inbreeding (mating exclusively within themselves), which often leads to the retention and expression of harmful recessive traits [1]. As such, characteristic genetic diseases such as Tay-Sachs and familial dysautonomia have long plagued the Jewish population, since the deleterious genes remain in the gene pool indefinitely.

The recent advent of premarital genetic testing has made significant inroads into reducing the prevalence of genetic disorders in the Jewish community. Genetic screening operates by obtaining a blood sample to test if an individual possesses recessive genes for a series of genetic diseases. Most genetic diseases result when a child inherits two recessive genes for the condition, with each parent contributing one copy of the defective gene. Thus, it is only problematic for a couple when each partner, termed a carrier, has one copy of the same deleterious recessive gene. If just one parent contributes a copy of the deleterious recessive gene, the child, albeit normal, has a 50% probability of being a carrier of the disease [2].

One of the largest and best-known programs for premarital genetic screening is Dor Yeshorim, which is Hebrew for “generation” (*dor*) of “the righteous” (*yeshorim*), which serves Jewish communities in America, Israel, and Europe. It was founded in 1983 by Rabbi Josef Ekstein of Brooklyn, NY, after four of his children died from Tay-Sachs disease, an autosomal recessive genetic disease. The organization visits high schools, as well as boy’s *yeshivot* and girls’ seminaries in Israel, obtain blood samples, and assign each participant an ID number. Dor Yeshorim tests for a suite of ge-

netic diseases, including Tay-Sachs disease, cystic fibrosis, Gaucher disease type I, Canavan disease, familial dysautonomia, Bloom syndrome, Fanconi anemia, glycogen-storing disease type 1a, mucopolysaccharidosis type IV, and Niemann-Pick disease type A. Most of these conditions occur with an elevated frequency among Jews of Ashkenazi origin.

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When the participants are of marriageable age and are either dating someone or have been suggested a *shidduch* (a potential match), each party exchanges ID numbers and contacts the Dor Yeshorim hotline. The ID numbers are reported to the operator, without exposing any personal information and, thereby, remain completely anonymous. The operator retrieves the records for each number and determines whether the individuals are carriers for the same genetic disease. If not, the couple is told that their marriage would be advisable; if carriers for the same disease, they are told that their marriage would be inadvisable. The specific disease for which the couple may be carriers is never disclosed at any time, thereby, maintaining complete confidentiality [3]. Since the inception of the organization, Dor Yeshorim has tested over 200,000 singles and informed 700 couples that their union would be inadvisable [2].

Premarital genetic testing, specifically as performed by Dor Yeshorim, raises a plethora of ethical questions from a secular vantage point. Firstly, by not informing the participants of whether they are carriers of specific genetic diseases, the system seems to take away the individual’s right to obtain personal information. Secondly, the program in-

fringes on the ability of people to freely choose their spouse, as Dor Yeshorim may inform them that it is not prudent to marry. Finally, not all the genetic diseases tested for by Dor Yeshorim are conditions that severely compromise the life of a child born with the disorder. While some are almost always fatal (like Tay-Sachs disease), the severity of other genetic disorders may depend on a variety of factors and may be mild and/or treatable. Therefore, it is questionable if a couple should be advised not to marry if they are carriers for a disease that is of a less debilitating nature.

When confronted with these challenges, Dor Yeshorim responds that the genetic screening conducted is a voluntary procedure that communities have adopted of their own free choice. Thus, no rights have been taken away from the participants. In addition, the completely confidential process in which the identity of the specific genetic disease is not specified prevents stigmatization of those who are carriers. Finally, and most importantly, the screening process is the only manner in which Jewish families can avoid the extreme anguish of having children with tragic physiological pathologies. This, after all, was the original goal of the founder, who experienced first-hand what it means for a family to be devastated by a genetic disease [3].

For observant Jews, genetic screening presents not just ethical questions but *halachik* issues as well. According to the *Zohar* (*Genesis* 7:11), in the latter part of the sixth millennium, “the gates of wisdom will open on high and fountains of wisdom will open below” in preparation for the anticipated Messianic era in the seventh millennium. According to the Jewish calendar we currently are living towards the end of the sixth millennium and, as such, it is appropriate from a Torah perspective that long-standing mysteries in science are now being uncovered. The Human Genome Project will map out and identify every gene in the human being and is one example of the increasing wisdom granted to mankind in preparation for the future. Furthermore, according to the Rambam’s interpretation of the *mitzvah*, “And you shall love the Lord your G-d” (*Deuteronomy* 6:5), as explained in *Hilkhot Yesodei HaTorah*, 2:2, the knowledge and the love of G-d is intrinsically linked. The only way for humans to “know” G-d and thus come to love Him, is through a thorough understanding of His creations, again reinforcing the importance of advances in science.

However, while genetic mapping may lie in the realm of gaining understanding in science, having one’s own genes screened does not fall under the same category. Therefore, if tests are available, as they are in premarital genetic screening, is one required to participate? One would not be contributing to scientific exploration. But on the other hand, one may be able to avoid transmitting genetic diseases to future offspring. Rav Moshe Feinstein addressed this issue around the time when Tay-Sachs testing was first being implemented (*Iggerot Mosheh, Even ha-Ezer*, IV no. 10). While he acknowledged the argument that one should simply trust in G-d when it comes to such matters, he did not feel that is applicable when it comes to genetic testing. Indeed, he regarded that failure to undergo such a test was equivalent to “closing [one’s] eyes [in order not] to see that which it is possible to see.” Furthermore, he encouraged precautions to be taken to ensure patient confidentiality and thereby to avoid stigmatization of carriers, since not everyone will understand that being a carrier does not pose a threat to their health. Dor Yeshorim certainly incorporated Rav Feinstein’s advice with its completely confidential system [4].

Despite the seeming *halachik* approval of premarital genetic screening, it is important to recognize that post-marital screening is not always permissible. Many leading rabbinical figures, including Rav Malkiel Kotler (a *Rosh Yeshiva* of the Beth Medrash Govoha in Lakewood, NJ) and Rav Shmuel Kamenetsky (*Co-Rosh Yeshiva* of the Talmudical Yeshiva of Philadelphia, PA) expressly forbid genetic and chromosomal tests on pregnant women to determine illnesses and deformities in their fetuses. Such tests are forbidden because Torah law almost never allows for abortions, except under very extreme circumstances [4]. Therefore, Rav Feinstein forbade the use of amniocentesis to diagnose fetal Tay-Sachs disease, since the physician may encourage abortion of such a fetus [5]. However, if the tests serve a constructive purpose, such as for treating the fetus *in utero* or for preserving the mother’s health, then such tests are allowed [4].

Examination of both the ethical and *halachik* perspectives on premarital genetic screening supports the endeavors of genetic testing organizations such as Dor Yeshorim. With G-d’s help, the continuing advancement of genetic testing and further knowledge of genetic disorders will one day eliminate all such conditions from the Jewish population.

ACKNOWLEDGEMENTS

I would also like to thank my husband Yoni for his continuing encouragement of my academic endeavors. Also, I would like to thank Dr. Babich for providing me with information to write this article, as well as his assistance with proofreading the content.

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